

Avoiding Crisis Support Needed

Justice Together Project with Bringing Us
Together and Respond



A parent survey
July 2016

Justice Together

Avoiding Crisis – A Parent Survey on Support Needed

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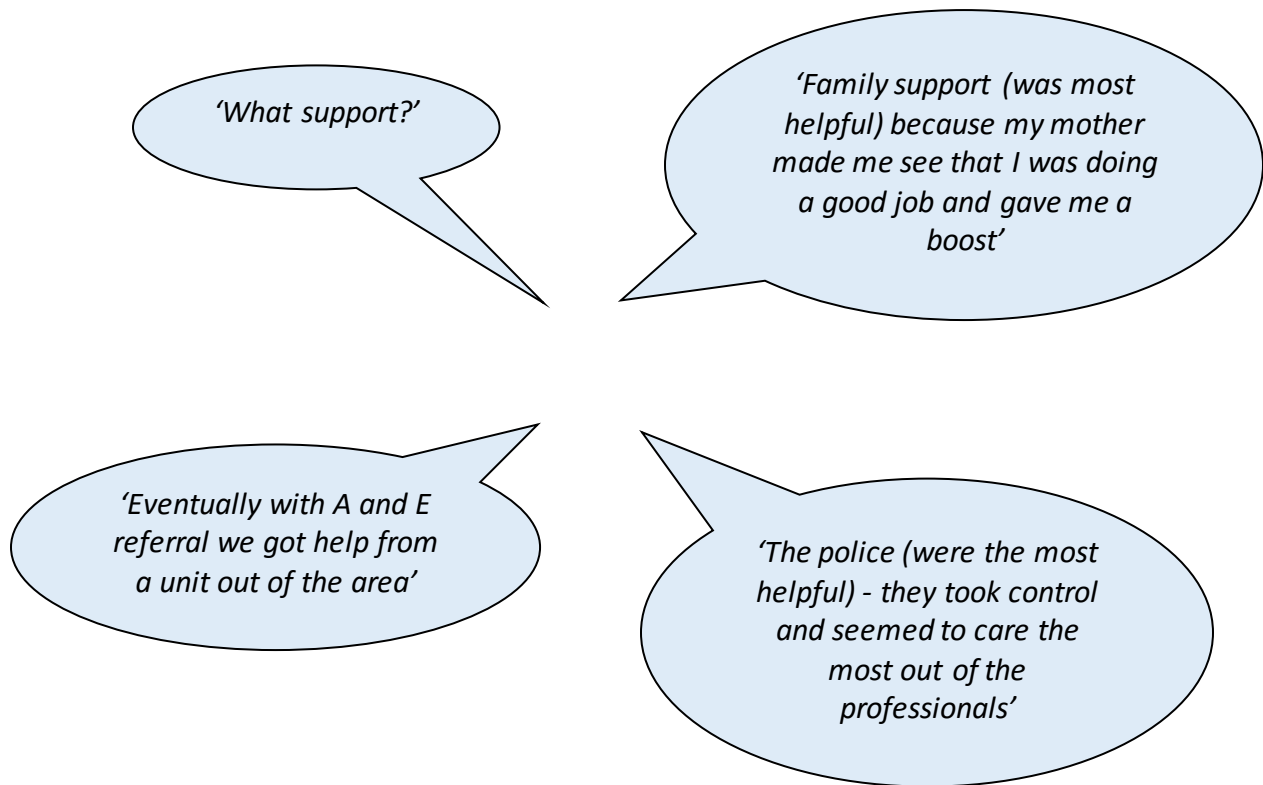
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Justice Together

Avoiding Crisis – A Parent Survey on Support Needed

Executive summary

What families said about the support they received in crisis:



1. Introduction

Respond and Bringing us Together are working in partnership to provide information and support to families of disabled children and young people who are approaching or who are currently in crisis.

A survey of families carried out in late 2015/2016 received responses from families across the whole of England, and it was striking that 24% of the people represented were under the age of 10, and 66% were under the age of 18. Respondents therefore reflected predominantly young people and their families, and it is very significant that a high number of these families have already experienced at least one crisis.

2. Findings

Some of the responses were shocking, only just over half of the families reported being given any advice on where to seek help, and even when given advice some families were too exhausted by the caring role to follow it up.

Even when advice and guidance was given, families often found that help was hard to get and inadequate. Generally telephone help lines were not felt to be useful, while internet access, discussion groups and support from other parents were felt to be more helpful.

When families actually found and accessed support there was a 50/50 split between those who found the support package helpful and those for whom it was not helpful.

Families identified emotional support, specialist advice, circles of support, advocacy and legal advice as the top priorities to sustain and support them.

3. Action

On the basis of the survey Justice Together is proposing to develop a programme of support for families at two 2 levels:

Level 1 - focus on generic support for families approaching/in crisis that includes:

- Information gathering
- Counselling and support
- Access to a helpline

Level 2 - more intensive with a focus on 'Justice Circles'. This would be intensive advocacy work for a limited number of families.

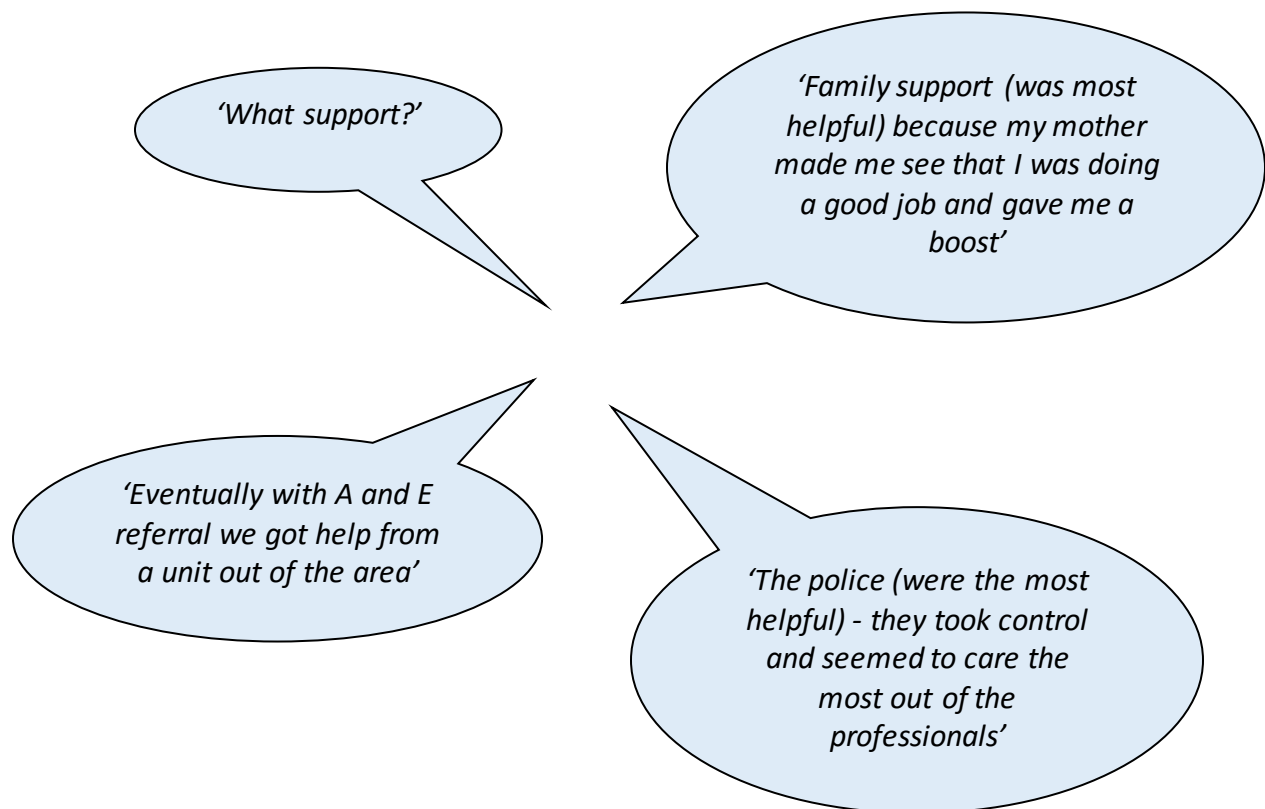
Justice Together

Avoiding Crisis – A Parent Survey on Support Needed

July 2016

Full Report

What families said about the support they received in crisis:



1. Introduction

Respond and Bringing us Together are working in partnership to provide information and support to families of disabled children and young people who are approaching or who are currently in crisis. The aim is to empower and support families to use the law to challenge services and ensure they make appropriate provision for the child or young person.

In the Winter of 2015/16 we carried out a survey which was completed by 86 families from across England. The families were approached via social media and mailing lists held by Bringing Us Together and Respond. The survey consisted of 14 questions in 4 sections, which covered:

- Basic information
- Experience of being in a crisis situation
- What would have helped
- Finding support

On the basis of the survey Justice Together is proposing to develop a programme of support for families at two 2 levels:

Level 1 - focus on generic support for families approaching/in crisis that includes:

- Information gathering
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Level 2 - more intensive with a focus on 'Justice Circles'. This would be intensive advocacy work for a limited number of families.

2. Response to the survey

The team received 86 responses from 53 different Local Authority areas across the whole of England, and the age range of the person with a disability was between 4 and 55. It is striking that 24% of the people represented here were under the age of 10, 66% under the age of 18 and 83% were under the age of 25. Respondents therefore reflected predominantly young people and their families, and it is also very significant considering the high number of families who have already experienced at least one crisis. Seven families had more than one member with a disability, and a large majority had autism and associated disabilities.

Full demographic data from the survey and the list of questions are in Appendix 1

3. How many families had experienced a crisis

The survey showed that fifty-seven people, representing 82% of those who replied to this question (and 66% of those who responded to the survey), had experienced a crisis and only seven reported that they had not.

Key Statistical Breakdown:

- 52% of those experiencing a crisis had a relative with autism, representing 33% of the total survey population
- 71% of families with a member with Down Syndrome experience crisis (7% of total population)
- 83% of families with a member with mental health needs recorded that they were unable to cope

The number of families who had experienced a crisis was especially concerning as those responding represented a 'young' population, with four fifths of the people being under the age of 25 years.

Experienced Crisis:

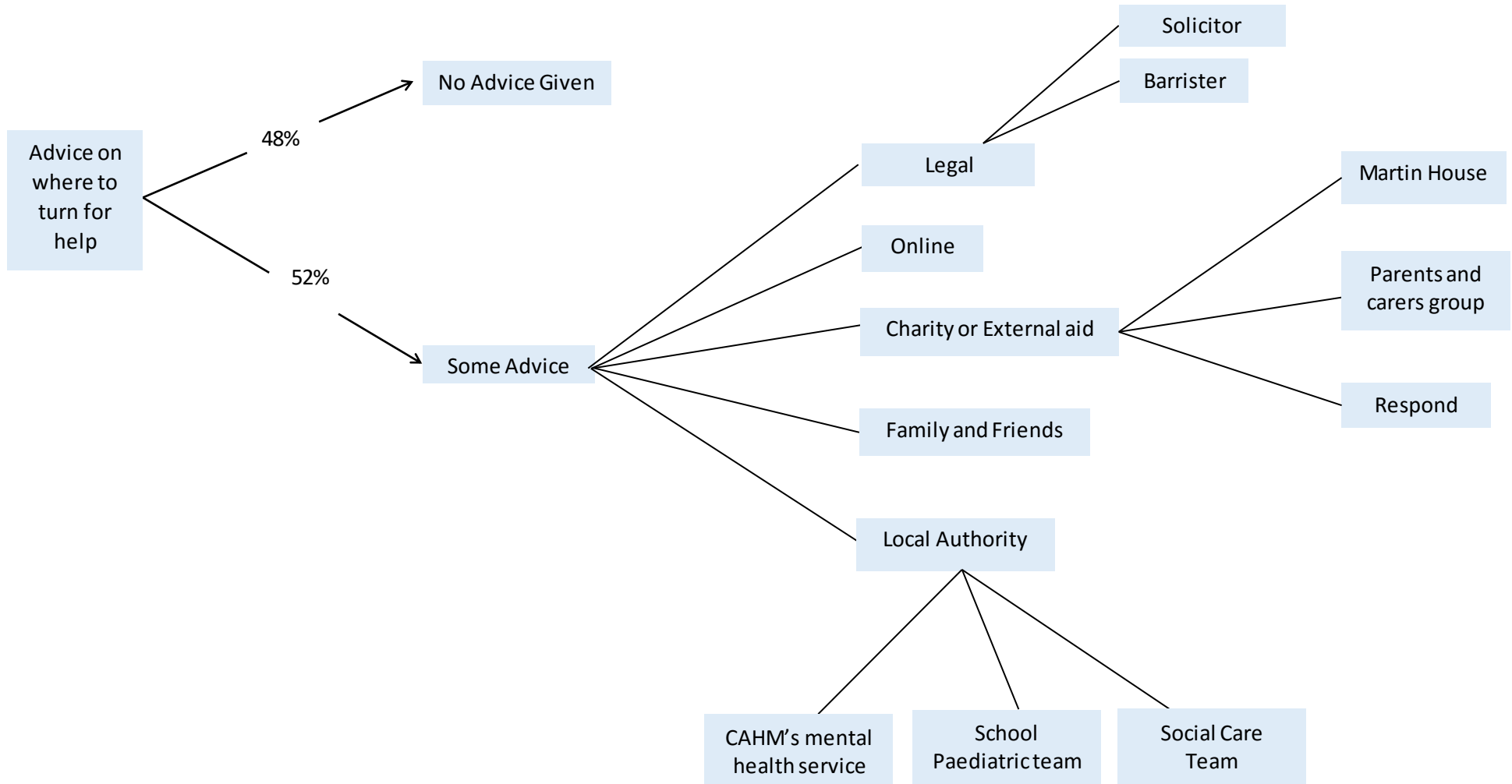
Age range	% experienced crisis
10 and under	50%
11 - 18	68%
19 - 25	50%
26 - 40	63%
41 and over	88%

4. What was the experience of seeking support?

4.1. Were families given advice and guidance about where to go?

Of the families who responded 48 % reported they were given no advice on where to go for help, and for some people advice did not necessarily lead to support being accessed.

The diagram below outlines the pathways followed:



For those who had no advice and guidance people said:

'No, (no advice) nor did I have the time or emotional strength to go looking'

'No (help) the caring role was too exhausting'

'No! I live on Anti-Depressants and Sleeping Tablets to cope.'

Of the people who sought advice and guidance there were mixed feelings:

'..... the support offered was inadequate'

'..... (it) was a chore getting at it'

'I have tried all the places that are supposed to offer support. It is all words, and shame the parent - never bother to meet the child! (For more than 5 minutes, when behavioural emotional and cognitive issues do not show)'

People were asked if they had used a telephone helpline at the time they were in crisis and 36% of those who responded to the survey had done so. No helpline came across as being particularly helpful; most comments indicated that no real value had been achieved by ringing the organisation.

'Helplines can signpost but can't provide the energy to process and cope'

Seventy per cent of those responding said they had used the internet and social media and mutual support groups.

'Internet Forum on Facebook. Very helpful in practical advice and support'

'Facebook support groups much better much more supportive and informative'

However for others it was more than they wanted.


'I found the internet too much. I was too emotional to read it all'

Talking to other families with similar experiences was commonly felt to have been very useful.

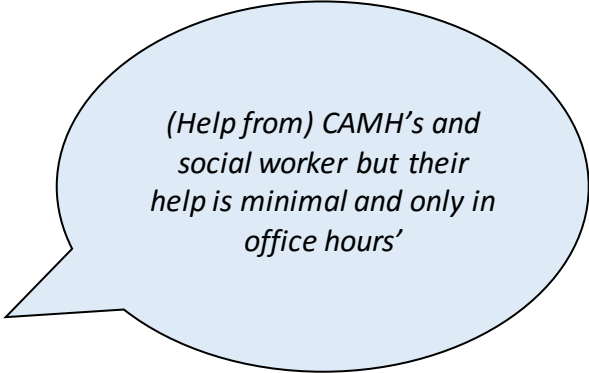
4.2. When people accessed support did they find it helpful?

Responses fell very clearly into two groups, one which received help, and the other who did not. Just over half the responders stated the support they had received was helpful. These responses related to both professional help and family support.

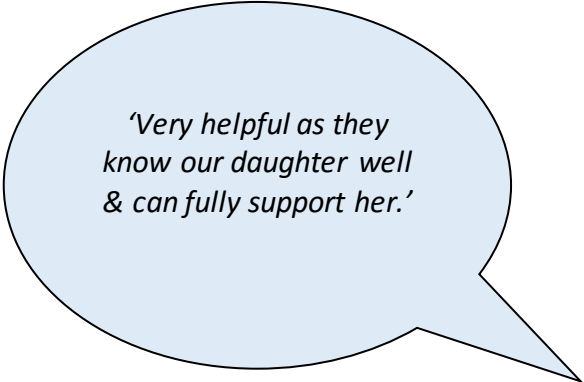
Analysis of the responses indicates varying levels of help, for example:



'Gave me ammunition', (this relates to Contact - a Family support)



(Help from) CAMH's and social worker but their help is minimal and only in office hours'



'Very helpful as they know our daughter well & can fully support her.'

For those people who felt they either did not receive any help or the help was not sufficient the story is very different as can be seen from the quotes below:

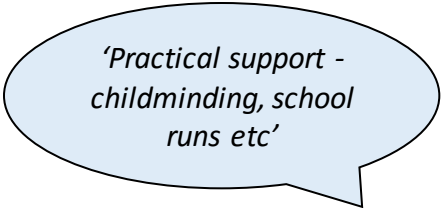
- *'Currently my son is in ATU now, wish Mencap and CBF help him out of ATU but how to support in community? LA is doing nothing, MP is nothing, no support at all'*
- *'No I felt like we were just passed along to the next service'*
- *'Social Services were too late in offering us support - resulting in son being sectioned. Mental health is a shambles - son is still waiting a transfer to be assessed and treated in an ASD-specific mental health hospital.'*
- *'We have tried to get support from EP, SS, Paeds, SALT, OT, CAMHS - they are all a waste of time.'*
- *'No not helpful. Too long for referral and assessments, no practical solutions or strategies just endless reports and meetings with no real plan to help me and those who care for me and no suitable therapy or support locally or affordable communication and behavioural help'*
- *'no they dumped me got text to say support finished, yet then when called them told the social worker for adult services had left and I had not been allocated anyone else 6+ months on no support, no contact from them'*
- *'No. No. It was all unhelpful. They blamed the parents and did nothing to help except some behaviour interventions for parents to do at home, which didn't work, because parents/home wasn't the problem. School was the problem.'*

5. The type of support participants found most useful

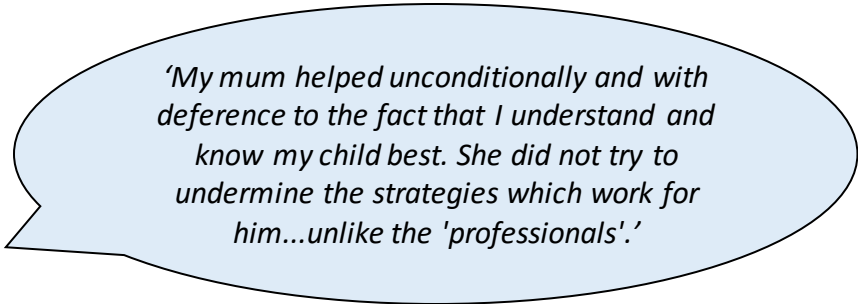
Many participants suggested that the practical support was often most useful in managing their lives. Family members were often leant upon as “practical help there and then when needed during crisis and meltdown [with] no restraints and no waiting for assessments”.

Nineteen people found support from professionals helpful, this includes some third sector options such as Martin House, Mencap, SCOPE and health professionals. Two people who found the police helpful.

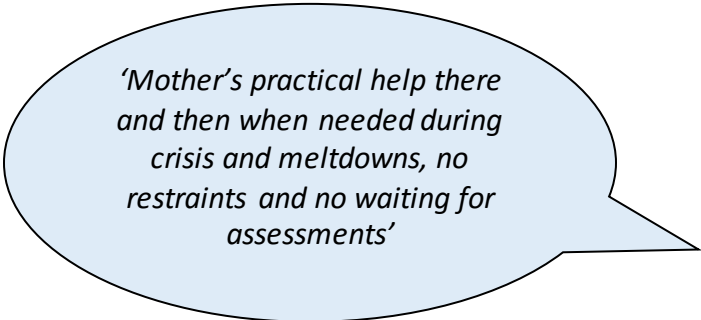
Furthermore, some respondents found themselves at A&E as they found that “no-one else was available”. For others, the access to legal information and support was a priority, hence needing professional support.



*‘Practical support -
childminding, school
runs etc’*



*‘My mum helped unconditionally and with
deference to the fact that I understand and
know my child best. She did not try to
undermine the strategies which work for
him...unlike the 'professionals'.’*



*‘Mother’s practical help there
and then when needed during
crisis and meltdowns, no
restraints and no waiting for
assessments’*

Two families reported seeking help from the police. The fact they had been unable to resource help from any other routes seems very unsatisfactory.

'If suicidal, call 999 for ambulance. If violent, call 999 for police'

Advice given by social worker, CAMHS and GP

'The police helped when things became extremely violent. Unfortunately social services refused to help, so on 1 occasion during a mental health crisis, my son was held handcuffed in a police cell for 4.5hrs because there was nowhere for him to go that could care for him.'

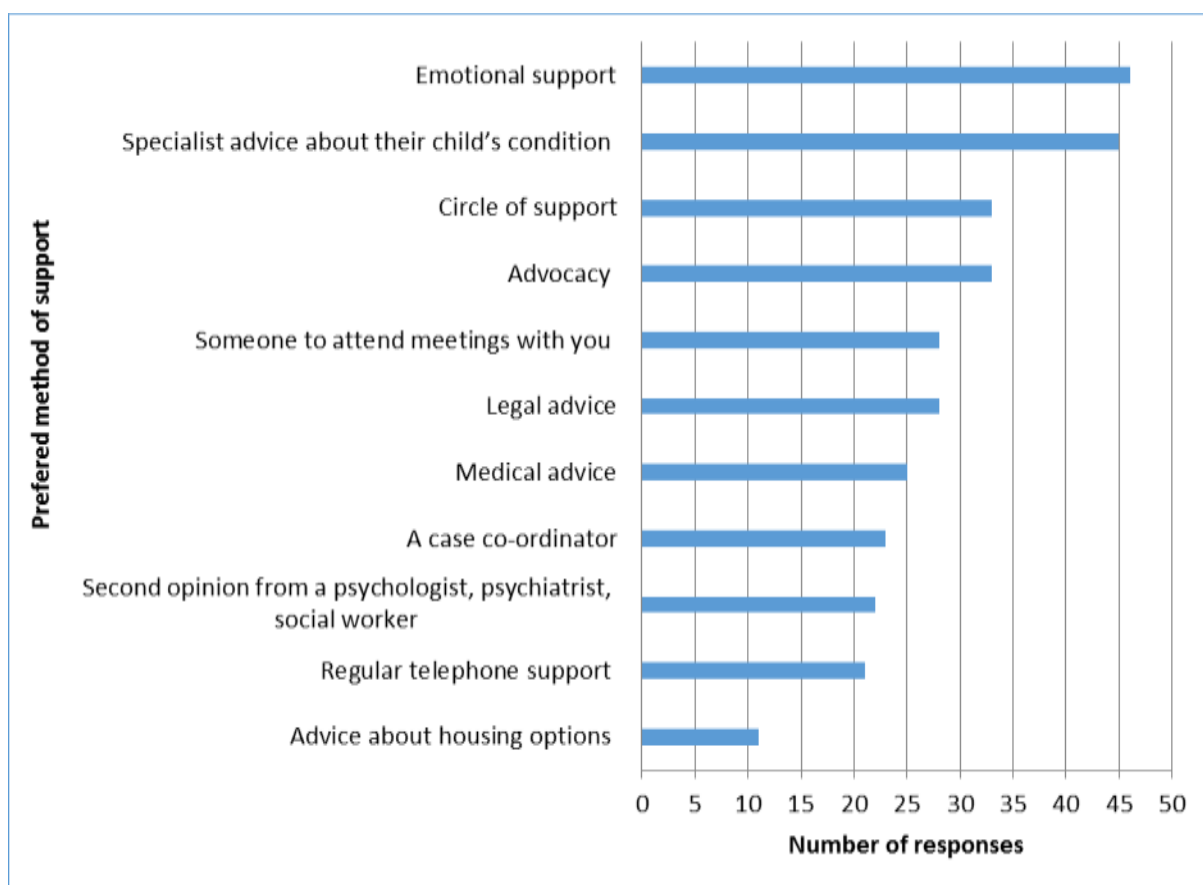
One person found themselves in A and E as that was the only option they felt they had for support in the crisis they were experiencing.

For a small number of other families the access to legal information and support was a priority, hence needing professional support.

Others found social media and peer support an invaluable help:

'Talking online mentally helped as I could chat to people who understood and it's easier to be honest with people a little removed from the situation Family and friends as offered practical support in the form of looking after my other (non-disabled) son.'

5.1. Families identified the following as types of support they felt would have been most useful



Other areas identified by families included respite, physical day to day support and specialist support about education options.

5.2. The 'Dream Team'

When asked to describe the dream team who would offer the best support to the family, the responses varied. Their answers included:

- A legally qualified advisor
- A barrister for tribunal
- Educational psychologist
- School representatives
- Personal advocate to attend meetings
- Specialist in different fields including:
 - Autism and ASD experts
 - Speech and language therapists
 - Visual impairment
 - Education

When asked about the characteristics of such a team, qualities such as being energetic, contactable, knowledgeable, caring, trustworthy, humanitarian and person centered were focal.

The approach was also preferred if the services were wrapped around the individual as opposed to trying to fit the individual into the rigid pre-existing service structure.

Communication between experienced professionals and inexperienced families was also highlighted as important especially such as that provided by 'Respond' particularly where abuse was part of the situation.

The Care Act (2014) places a duty on the Local Authority to provide a Universal information and advice structure or service for adults. 31 relatives were aged 18 or over, 48% of the total. This means effective information and advice should be available to this group of people to support them to make decisions about their care and support needs. Reflecting on the responses in the survey, we have much work still to do.

6. Conclusion

Some of the responses were shocking, only just over half of the families reported being given any advice on where to seek help, and even when given advice some families were too exhausted by the caring role to follow it up.

Even when advice and guidance was given, families often found that help was hard to get and inadequate. Generally telephone help lines were not felt to be useful, while internet access, discussion groups and support from other parents were felt to be more helpful.

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Thank you to everyone involved in this work, and in particular to:

All the parents who filled in our survey – we really appreciate the time you spent completing the form.

The Justice Together steering group – especially to Jeanette Thompson for her time

Lawrence Moulin, Will Ritchie Moulin and Carol King who came in to support us with putting the finishing touches to the report

Bringing Us Together Team – Debs and her wonderful ICT skills and getting the survey out there in the public domain.

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Appendix 1: Survey

Survey Responses:

We had responses from 86 families across England as shown below in Fig 1.



Fig 1.

Statistical spread of survey:

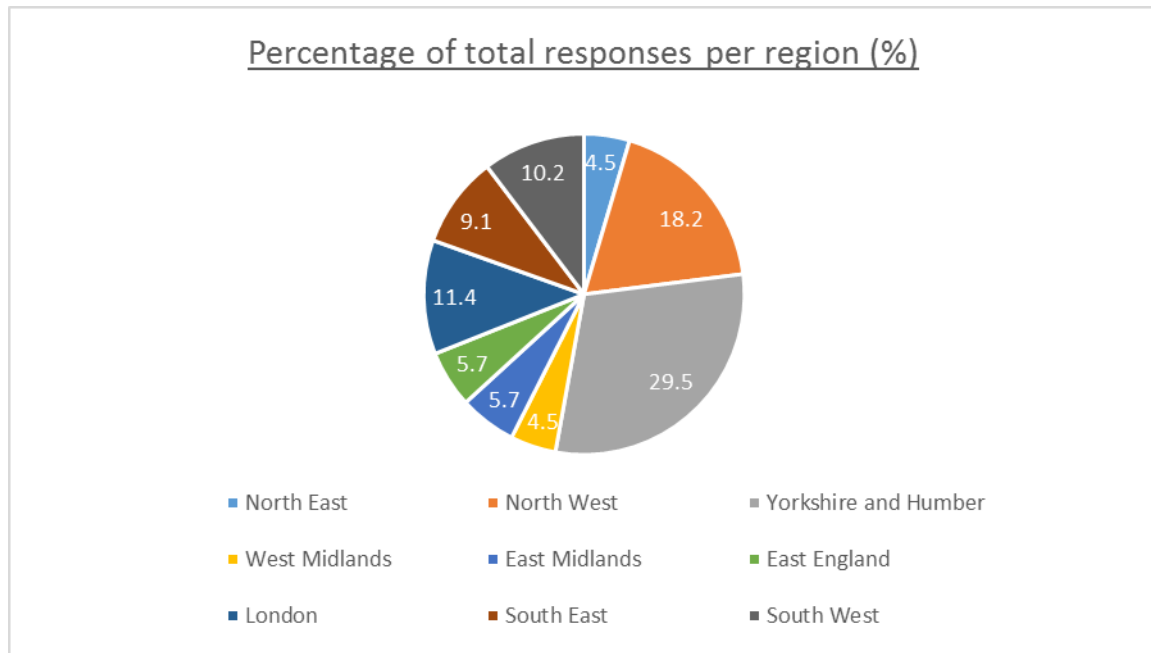


Fig 2.

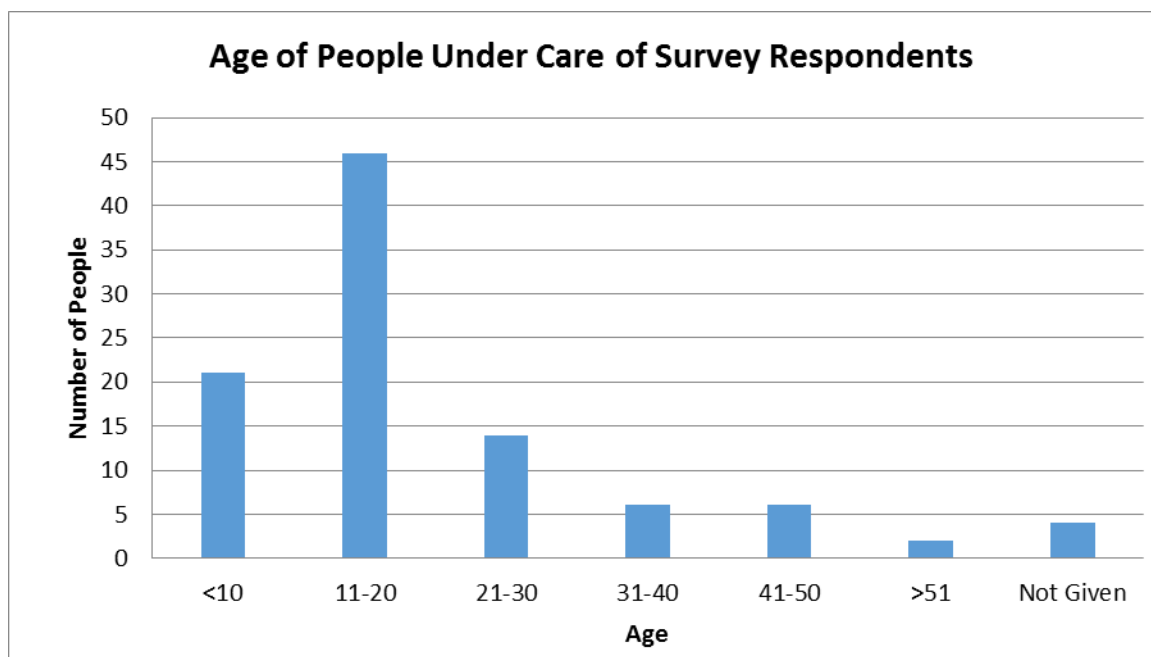


Fig 3.

Age range	Respondents
<10	20
11-18	41
19-25	16
26-40	8
Over 40	8

From Fig 3 we can clearly see that there was a large spread of ages of person with a disability, ranging from age four to fifty-five. This data is important because when the large number of families who stated that they were in crisis is considered there are a disproportionate number of young people represented.

Crucially, 24% of all the represented people were under the age of ten, 66% under the age of 18 and 83% were under the age of 25.

Clearly a focus must be made on establishing communication with families who have a young person with disabilities living with them, as they seem more likely to experience a feeling of crisis.

Type of disability:

Type	Number of people
Autism (and associated disabilities) *	37
Asperger Syndrome	4
Downs syndrome	7
Mental Health	6

*Associated disabilities include sensory processing disorder, learning difficulties/disabilities, communication delay, self-harm, epilepsy and anxiety disorder

Other respondents indicated the following diagnoses: attachment disorder, learning disability, Rett syndrome, Fragile X, Cerebral palsy, ADHD, fetal alcohol syndrome, visual impairment and neurological disease.

Survey questions:

Question	No. of responses
Which Local Authority do you (or your family member if you are completing on their behalf) live within?	86
How would you define your (or your family member's if you are completing on their behalf) disability?	83
How old are you (or your family member if you are completing on their behalf)?	83
Have you ever found yourself in a crisis situation?	69
Who was there for you in your situation? E.g. family, friends, professionals, services, charities (be as specific as you can about the organisations)	62
Which support did you find most useful and why	59
Was the support from any organisation you approached helpful (Please explain as fully as you can how it did or did not help having the support)	53
What sort of support did (or do) you need? (multiple choice)	58
Who else would you have liked to have been there/involved?	45
Did you know where to go for support	53
Were you given any advice/guidance as where to go and if so, who told you	51
Did you phone a telephone helpline (if yes, which one and how useful was it)	49
Did you find any support via the internet (if yes, what support and how useful was it)	45
If you could create a dream team of support, who/what roles would it include?	50

Appendix 2: Local reporting

Yorkshire and Humber

26 people from Yorkshire and Humber responded to the questionnaire, this included 10 different Local Authorities:

- East Riding of Yorkshire
- Sheffield
- Calderdale
- North Yorkshire
- Barnsley
- Leeds
- York
- Wakefield
- Kingston upon Hull
- Bradford

28 people between the ages 5 -38 with 22 people being under the age of 20. 12 families relied on friends and family for support, the remainder used schools, professionals and third sector to provide help and support. The usefulness of the support varied and provided examples where family members provided total support for individuals usually mum, husband or wife.

Five families did not find the support they received useful, Calderdale parents group was seen as useful. Others used third sector organizations to good effect. People from Yorkshire and Humber wanted the full range of support available, from medical through to circles of support. When identifying what additional support people required weekend support and co-ordinated support. Twelve people struggled knowing where to go for help, those that did did not necessarily find the help provided useful. Ten families used a telephone helpline, the lines used included NAS, DSA, Mencap, Mind, CBF, Contact a Family and Ipsea. Not all families reported the help lines as helpful. Nine families found help via the internet. Some used national websites such as NAS others used social media and found contact with other families helpful.

The dream team reflects that of the whole sample.

London

10 people from London responded to the questionnaire, this included 8 different Local Authorities:

- Haringey
- Lambeth
- Barnet
- Hackney
- Tower Hamlets
- Waltham Forest
- Hounslow
- Kingston upon Thames

11 people between the ages 4 -55 with 6 people being under the age of 20. All but two families relied on friends and family for support, 5 families used schools, professionals and third sector to provide help and support. The usefulness of the support varied and provided examples where family members provided total support for individuals.

Two families did not find the support they received useful, others talked about the lateness of the offer of help. Others identified it made the crisis more bearable and CAMHS being supportive. People from London wanted the full range of support available, from medical through to circles of support. When identifying what additional support people required it included, respite, independent psychiatrist or simply support rather than 'defensive hostility'. Most people struggled knowing where to go for help, those that did didn't necessarily find the help provided useful. All but three families did not have any help to understand where to go for help. Only two people used a telephone helpline, the lines used included Samaritans, NAS, Contact a Family and Ipsea. Only four families found help via the internet. All four families focused on social media and mostly parents or related groups.

The dream team reflects that of the whole sample.

Appendix 3: Additional comments

- *The support was limited due to resources*
- *None - unresponsive professionals over 3 years, drugs, no appointments offered to support him*
- *No not helpful. too long for referrals and assessments. No practical solutions or strategies just endless reports and meetings with no real plan to help me and those who care for me and no suitable therapy or support locally or affordable communication and behavioural help*
- *The education system was damaging for us and caused so many problems that will be with us for life. Schools take no responsibility and are not held accountable, despite receiving £millions of public money. The education system needs a complete overhaul in order to stop it from ruining the lives of children, young people and families*
- *The system is a labyrinth. No clear care pathway available or even known to families*
- *Help with organising short breaks which I didn't know existed - I had no idea of what help was available or where to look for it. Having short breaks helped to keep our family together*
- *Respite break as continually caring for our son 24:7, whilst trying to save him from LA, is taking its toll on our health*
- *We also needed training courses! And we needed help at home. All the help seems to be for school. Not one professional has ever been to my house. We also needed respite care*
- *A coordinator, keyworker has always been missing. Regular nights sleep would be invaluable*
- *Physical day to day support ie respite or help around the home. His care needs were literally 24/7 so I was trying to cope with two children under 2yrs with no sleep.*

- *Support instead of defensive hostility would have made a huge difference*
- *An advocate of my choosing – not one provided and funded by the LA*
- *At the time of crisis it would have been good if health and social care had been in touch. I had to keep repeating my 'story' to people who came to assess us. A holistic approach to our family with good communications between different services would have been really good. At its worst the Health Visitor seemed to be the person who held me together.*
- *I would have liked support for myself and my family whilst trying to get my son properly assessed instead I got accusations, threats from professionals and then had to pay for my sons assessments but still got no support. Still paying for next assessment. No help implementing explosive child strategies, have paid to go on courses to help me understand my little boy more, there's no support here.*
- *Someone on 'our' side, who could fight for our son, who bothered to get to know him rather than read inaccurate paperwork, someone who cares about his thoughts, feelings and wishes*
- *The main problem has been in getting any 'professional' to take it seriously: they just pass the buck*
- *Only after searching for it. Thank god for the Internet*